

Facts about...

Division of Cancer Control and
Population Sciences (DCCPS)
<http://cancercontrol.cancer.gov/>



Office of Cancer Survivorship (OCS)

Applied Research Program
(ARP)

Health Services and
Economics Branch (HSEB)

Outcomes Research Branch
(ORB)

Risk Factor Monitoring and
Methods Branch (RFMMB)

Behavioral Research
Program (BRP)

Applied Cancer Screening
Research Branch (ACSRB)

Basic Biobehavioral
Research Branch (BBRB)

Health Communication and
Informatics Research Branch
(HCIRB)

Health Promotion Research
Branch (HPRB)

Tobacco Control Research
Branch (TCRB)

Epidemiology and Genetics
Research Program (EGRP)

Analytic Epidemiology
Research Branch (AERB)

Clinical and Genetic
Epidemiology Research
Branch (CGERB)

Surveillance Research
Program (SRP)

Cancer Statistics Branch
(CSB)

Statistical Research and
Applications Branch (SRAB)



Office of Cancer Survivorship National Cancer Institute

<http://survivorship.cancer.gov>

WHO WE ARE

The Office of Cancer Survivorship (OCS) was established in 1996 by the National Cancer Institute in recognition of the large number of individuals now surviving cancer for long periods of time. The OCS is dedicated to enhancing the length and quality of life of the estimated 9.8 million cancer survivors in the United States¹ and addressing their unique and poorly understood needs.

The OCS considers an individual a survivor from the time of diagnosis through the balance of his or her life. Because friends, family members, and caregivers are also affected by a cancer diagnosis, they are included in this definition as well.

CANCER SURVIVORSHIP FIGURES

- As of January 2001, it is estimated that there are 9.8 million cancer survivors in the U.S., representing approximately 3.5% of the population.¹ Approximately 14% of the 9.8 million estimated survivors were diagnosed more than 20 years ago.

- Three out of every four American families will have at least one family member diagnosed with cancer.²

- Today, 64 percent of adults diagnosed with cancer will be alive in five years. Among children, nearly 75% of childhood cancer survivors will be alive after 10 years¹.

WHAT WE DO

The OCS supports and promotes research that examines and addresses the long- and short-term effects of cancer and its treatment. These include physical, psychological, social, and economic effects among pediatric and adult survivors and their families. Survivorship

research focuses on the physical, emotional, social, and financial outcomes, beyond the treatment phase, and seeks to optimize the health and well-being of persons living with a history of cancer. Survivorship research also seeks to provide a knowledge base regarding optimal follow-up care and surveillance of new or recurrent cancers.

The OCS provides information to cancer patients, their families, healthcare providers, advocates, and the research community. We maintain an extensive Web site with current information on survivorship issues. The OCS does not provide direct service delivery to patients. (For information on direct services, see *Service-Related Cancer Organizations*.)

The OCS conducts meetings with researchers, health professionals, advocacy groups, cancer survivors, and the public to build common research agendas and ensure dissemination of research findings. We partner with other offices within the National Cancer Institute (NCI) and across the National Institutes of Health (NIH) to stay abreast of the most current research in areas affecting cancer survivorship and to be a voice for survivorship issues.

The OCS conducts an annual analysis of the NIH grants pertaining to cancer survivorship. We look at what is being studied and compare this with cancer trends and requests for research from the public and scientific communities. This helps ensure that our research goals respond to the needs of survivors. From this analysis, we can create recommendations for future research funding.

RESEARCH ACTIVITIES

Research supported by the OCS focuses on many aspects of survivorship. Our primary research categories and examples of questions being addressed are provided below. For a more comprehensive description of survivorship research, see the OCS Web site.

- **Physical Effects.** How many survivors experience lymphedema, incontinence, memory problems, pain syndromes, or fatigue? Are there personal or medical factors that increase a survivor's risk for developing these conditions? What is the incidence of second cancers in patients who are treated?
- **Psychological/Psychosocial.** How do cancer survivors adapt to the personal and social consequences of diagnosis and treatment? How common is depression after cancer? Does stress cause cancer recurrence?
- **Health Disparities.** Do sociocultural variables (socioeconomic status, geographic location, minority status, etc.) affect the quality of life and other aspects of cancer survivorship? If so, how should cancer professionals respond to this?
- **Intervention Research.** How do education, lifestyle (e.g., diet, physical activity), behavior (e.g., coping skills training), and support (e.g., group therapy) affect a survivor's quality of life or length of survival? Do drug or alternative medicine interventions improve outcomes?
- **Family Issues.** How does cancer affect family members and caregivers across the life span—siblings of cancer patients, parents of cancer patients, children of parents with cancer, spouses and partners caring for partners with cancer, and adult children caring for elderly parents with cancer? Do interventions to help family members cope improve the cancer survivor's health?
- **Financial Burden.** What are the relative costs of cancer care? What is the economic impact of variations in survivor health? What are the trends in medical or follow-up care costs?
- **Cancer Communication.** Does access to new media and technology improve the distribution of cancer information? What information needs to be shared between survivors and healthcare providers? How should this be delivered? How can we stay in touch with cancer survivors once they leave routine treatment?

• **Instrument Development.** What is the best way to evaluate survivors' health? How can we compare the quality of life of cancer survivors with that of others with chronic or life-threatening illness? Are there benefits to survivorship and how do we measure these?

HOW TO FIND US/CONTACT US

You can learn more about the Office of Cancer Survivorship on our Web site at

<http://survivorship.cancer.gov>. Tools for survivors and their families can be found by clicking on "Post-Treatment Resources" There you will find such resources as *Facing Forward: Life After Cancer Treatment*, *Siga adelante: la vida después del tratamiento del cancer*, and *Ways You Can Make A Difference in Cancer*. These booklets provide a concise overview of survivor issues post-treatment such as ongoing health needs, how to deal with your feelings, insurance, and employment, and information on getting involved with cancer-related activities.

SERVICE-RELATED CANCER ORGANIZATIONS

The Office of Cancer Survivorship is a research office and does not provide direct services to the public. Here are some resources that can address questions regarding diagnosis, treatment, and survivorship issues.

- NCI Cancer Information Service
1-800-4-CANCER (1-800-422-6237)
TTY 1-800-332-8615
- NCI Online
<http://cancer.gov>
- American Cancer Society
<http://www.cancer.org/>
- CancerCare
<http://www.cancercare.org/>
- Fertile Hope
<http://www.fertilehope.org/index.cfm>
- Lance Armstrong Foundation
<http://www.laf.org>
- National Comprehensive Cancer Network
<http://www.nccn.org>

¹US 2001 cancer prevalence counts are based on 2001 cancer prevalence proportions from the SEER registries and 1/1/2001 US population estimates based on the average of 2000 and 2001 population estimates from the US Bureau of the Census. Prevalence was calculated using the First Malignant Primary Only for a person.

² Cancer facts and figures 1996. New York, American Cancer Society, 1996.